

# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 222. Summer 2023

We're bringing back  
this year's annual  
conference in person

# REJUVENATE



**BREAKING NEWS**

# Omaveloxolone now approved

For more information on the first Friedreich's  
ataxia treatment, SKYCLARYS, see page 8

Supported by



- Annual Conference • Ataxia People
- Research • Individual giving • Fundraising
- Living with ataxia • Services

# ATAXIA

Ataxia UK

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## In the office



It is with heavy hearts that we're saying goodbye to **Stephanie Lawrence**, our **Head of Finance**. Stephanie has been a member of the team for over 6 years and in that time she's given the ataxia community extraordinary devotion and delivered fantastic work behind the scenes. Most Friends will likely remember her from our Annual Conferences where she always went the extra mile to make sure Friends felt welcomed and that they were greeted with a smile. We wish Stephanie all the best in her next challenge and hope to see her back for one of her legendary quizzes.

## CEO's Introduction

After so many years waiting for the discovery and approval of treatments for the ataxias, it's such good news that **Omaveloxolone** (now known as **SKYCLARYS**) has received drug approval in the USA. Unfortunately, it seems we're going to have to wait longer for it to be available in the UK. See page 8. We want to reassure everybody that we're doing all we can to press for this to happen as soon as possible.

It's excellent news that **Eilidh Clark** joined us at the beginning of April. **She will deliver our new Scottish Advice Service which is now available to all Scottish Friends in partnership with Glasgow Parkhead Citizens Advice Bureau** where Eilidh is based. See page 22 to learn more about how she can help you if you live in Scotland.

**I'm so pleased to be able to invite everybody to our Annual Conference to be held on Friday 20th & Saturday 21st October at the Radisson Blu East Midlands Airport.**

Yes! It's definitely happening this time! I hope to see many old faces and lots of new ones. If it's your first time, don't worry, you will find a friendly welcome. We have an exciting programme prepared for you, so go to page 4 for more information. **But hurry! We have to start returning unbooked hotel rooms by 22nd June after which we can't guarantee their price! Book your face-to-face (or hybrid) tickets and I'll see you there!**

Best wishes,

Sue Millman



Sue

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## Annual Conference

- 2023 Annual Conference: save the date!
- Award nominations needed! ————— 4



## Ataxia People

- Become a Trustee of Ataxia UK ————— 7



## Research

- SKYCLARYS – drug to treat FA
- Diagnosis and management of gluten ataxia ————— 8



## Individual giving

- The First 272 Steps...
- The new Memorial Tree ————— 12



## Fundraising

- Fundraising thank-yous
- Ataxia Classic 2023 ————— 14



## Living with ataxia

- Travelling and ataxia
- London Fashion Week in wheels ————— 17



## Services

- How to apply for a grant
- Volunteers Week ————— 21



# Annual Conference 2023

We are delighted to bring you the Annual Conference 2023, which for the first time ever, will be a combination of in-person, and online! It will take place at the Radisson Blu, East Midlands Airport on Friday 20th and Saturday 21st October.

We are very much looking forward to welcoming as many of you as possible in-person. If you are unable to attend in person, we will be streaming the most important parts of the conference straight to your living room, as well as some interactive sessions for virtual attendees.

On Friday you can attend an **All About Ataxia** session from 11.30 – 5pm. (See the panel on page 6). Saturday's programme runs from 9.30am to 5pm followed by our formal evening dinner and after-dinner entertainment.

**Bookings for conference tickets, hotel rooms and bursaries will open on 7th June at 9:30am. Read on for more information on the conference, pricing, programme, All About Ataxia, or visit our website at: <http://alturl.com/2bpdu>**

## PROGRAMME

We look forward to bringing you a packed conference programme on **Saturday 21st October**, including It Works for Me sessions with Friends of Ataxia UK, a range of interesting keynote speakers, presentations, Doctors' Q&As and Research updates on Friedreich's ataxia and Cerebellar ataxia and a variety of hands-on sessions including yoga, mindfulness, genetic testing and so much more... Plus, not to forget the highlight in the form of the formal dinner & after-dinner entertainment. **To stay up to date with the agenda make sure you're signed up to our monthly eNews or visit the dedicated conference page on our website.**

## BURSARIES

We want as many people as possible to be able to attend in-person. With the prices of everything being higher than the last time we had an in-person conference, we're increasing the number of bursaries for people on means-tested benefits. If you're eligible you can claim 50% of accommodation, travel and conference tickets for someone with ataxia, plus a carer if required. **Bursaries are on a first come-first-served basis. If you would like to apply for a bursary, you can do so by visiting <http://alturl.com/2bpdu> or phoning 0207 582 1444 from 9:30am, Wednesday, 7th June.**

## BOOKINGS

**Bookings will be online from 9:30am, Wednesday, 7th June for conference tickets, dinners and bursaries at <http://alturl.com/2bpdu>. If you are unable to book online, you can call 0207 582 1444 and one of the team would be happy to assist you.**



## HOTEL ACCOMMODATION

**You will need to book your own accommodation at the hotel, unless you need an accessible room, in which case see below.** We can only guarantee the price we have negotiated until 22nd June. But don't worry, FREE CANCELLATION is included up to 7 days before the conference. **So, HURRY! Book before 22nd June to ensure you receive the room at the special conference rate!** There are several other cheaper hotels within a few minutes' walk, at which you may find slightly cheaper accommodation.

To book a standard / non-accessible room at the conference hotel, please contact **Jessica Ridley** on: **01509 686246** or **jessica.riddell@radissonblu.com** and quote **'Ataxia UK Annual Conference 21st October 2023'** so that you receive the discounted rate for conference attendees.

Additionally, everyone that uses the quote when booking a room at the Radisson Blu will also receive a £30 discount nightly discount at the time of booking! If you're booking a room at one of the overflow hotels, please contact the team at **conference@ataxia.org.uk** with your receipt and you will be reimbursed £30 per night.

### Disabled accessible rooms ONLY: BOOK THROUGH ATAXIA UK.

There are a limited number of disabled-accessible rooms. We have reserved all of them at the Radisson Blu, and we have also reserved disabled-accessible rooms in nearby hotels, several of which have interconnecting rooms for a carer if a separate room is required.

To book a disabled accessible room ring **0207 582 1444** or email **conference@ataxia.org.uk** from Wednesday 7th June, saying who you are, whether you are a wheelchair user or not, whether you are bringing a carer, if you require a wet room or if a partially accessible room is sufficient, and which nights you wish to stay.



### XDN – RADISSON BLU FULLY ACCESSIBLE BEDROOM ROOM FEATURES:

- Queen size double bed
- Larger floor space
- Wet room bathroom
- Seat in shower area
- Grab handles in shower area
- Heat controlled shower & taps – the water will never come out too hot
- Lower Hand wash sink, Automatic heat-controlled taps
- Additional lower vanity sink
- Accessible toilet
- Grab rails around toilet
- Grab rails in bathroom area
- Pull cord for emergency use (connected to reception)
- Lower spy hole in door

### XKN – RADISSON BLU SEMI ACCESSIBLE BEDROOM ROOM FEATURES:

- King Sized Bed
- Slightly larger floor area
- Shower (with small lip to access)
- Heat controlled shower – the shower will never run too hot
- Automatic heat-controlled sink taps
- Bathroom Standard size, toilet behind standard width door



PRICES	Price	No. of people	Total
Friday 'All About Ataxia'	£25		
Friday Buffet	£19		
Conference ticket Person with ataxia	£40		
Conference ticket Person without ataxia	£43		
Saturday Dinner	£39		
Friday night hotel room at conference venue (single, breakfast incl.)	£115		
Friday night hotel room at conference venue (couple, breakfast incl.)	£125		
Saturday night hotel room at conference venue (single breakfast incl.)	£115		
Saturday night hotel room at conference venue (couple, breakfast incl.)	£125		
Interconnecting room bed & breakfast rate for carer (limited availability)	£100		
<b>Total booking cost</b>			
<i>Total cost of a ticket for both days of the virtual conference</i>	£15		

Overflow hotel room prices start from: **Travelodge: £88.99, Holiday Inn Express: £104.99, Elite Athlete Centre: £120.50, Burleigh Court: £132.30, Hilton East Midlands: £135.00, Premier Inn: £138.50**

## Award nominations needed!

### Ernie Heath Award and Matthew Law Awards – group or individual award nominations needed!

Every year Ataxia UK makes 3 awards to celebrate the particular achievements or commitment to the ataxia community to: a Branch or Support Group, someone affected by ataxia (Ernie Heath Award); and someone who has the condition (Matthew Law Award).

If you have anyone you'd like to nominate for the awards, please send your nominations to **conference@ataxia.org.uk** with the nominee's name and their contributions to the ataxia community.

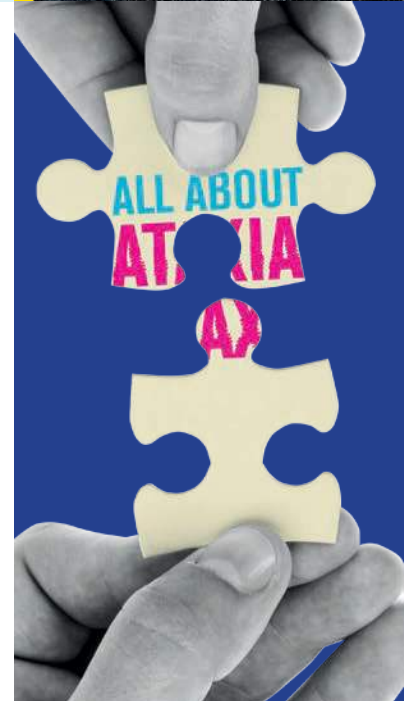


## All about ataxia

**Do you have a recent ataxia diagnosis? Or do you simply want to know more about ataxia? All About Ataxia is your opportunity to hear robust information from clinicians and therapists about what is known about ataxia, and to discuss your challenges with other people who are in the same situation as you.**

The programme will be facilitated by people with diagnoses of ataxia who have been trained to deliver the programme. They will share their life experiences and offer tips and coping strategies. Between them, they have over 60 years' experience of living with an ataxia diagnosis! Although they all have different ataxias, backgrounds, ages and circumstances, they are all proof that a diagnosis of ataxia doesn't mean the end of ambition or achievements in life.

Book your tickets by heading over to our website from 9:30am, Wednesday, 7th June: **<http://alturl.com/2bpdu>**



# Become a Trustee of Ataxia UK

## Have you the vision, commitment, and experience to be a Trustee of Ataxia UK?

The Trustee Board governs and sets the strategic direction of Ataxia UK. Trustees oversee every aspect of Ataxia UK's operation, including finance, services we offer, the research we fund, and how we fundraise. It ensures that the charity is financially viable and has robust policies and procedures covering every area of our operation.

The Board is made up of Friends of Ataxia UK; seven who are elected by Friends of Ataxia UK and three who are appointed by the Board and co-opted. It meets 4-5 times a year mainly on Zoom but once a year face-to-face/hybrid, meetings are from 11am – 3.30pm.

**We have vacancies on the board for Trustees. In particular, we are looking for someone with fundraising or marketing experience, or someone with medical/clinical experience.** All posts are subject to interview and the elections take place in September, there are several vacancies for co-optees.

We are particularly keen to broaden the diversity of our Board Members to ensure we have a range of perspectives at meetings and would particularly encourage people who come from non-white backgrounds or are members of the LBGTQ+ community to apply for these roles.

*You can find more information including a Job Description by visiting [www.ataxia.org.uk/work-for-us/trustee-jd](http://www.ataxia.org.uk/work-for-us/trustee-jd). Anyone interested will be welcomed at an online information seminar with the **Chair of Trustees and Sue Millman**, please let Sue know of your interest by emailing [smillman@ataxia.org.uk](mailto:smillman@ataxia.org.uk).*

# SKYCLARYS – the first drug approved to treat FA

**On 28th February 2023, we heard the excellent news that Omaveloxolone (now known as SKYCLARYS) was approved for the treatment of Friedreich's ataxia (FA) in over 16s in the United States.**

As the first drug approved to treat FA, this is a huge step for the entire community, and we are so pleased that people living with FA in the US will soon have access to this treatment.

**It is Ataxia UK's priority to ensure that people with FA get access to the drug in the UK, too.**

We are doing everything we can to support and encourage Reata Pharmaceuticals to seek approval for SKYCLARYS in the UK. To drive forward the approval process in the UK, we have set up an FA Special Interest Group, which includes clinical experts, Ataxia UK staff, and parents of children with FA. The group is meeting regularly and developing an action plan. Please make sure you sign up to our dedicated newsletter at [www.ataxia.org.uk/omav-updates](http://www.ataxia.org.uk/omav-updates) and keep an eye on your inbox as there may be ways for you to help with supporting this plan in the future.

**We were very pleased to hear that Reata applied to the regulators in Europe (the EMA) at the end of 2022. However, if the EMA approves SKYCLARYS, this will not automatically result in approval in the UK. To make SKYCLARYS available in Great Britain, Reata will need to apply to the MHRA (UK regulators).** The MHRA is developing a framework to enable drugs approved in some countries, including by the US, to be fast-tracked for approval in the UK. The Chancellor said in his budget speech that there would be 'near-automatic sign-off' of drugs approved by trusted regulators such as the FDA in the USA. This is really good news, although it will not be implemented until 2024. In Northern Ireland drugs currently go through EMA approval, but under the Windsor Framework (a post-Brexit legal agreement between the EU and the UK,) this will change, and medicines would be regulated by the MHRA.

Prof Paola Giunti and her team at UCL, were involved in laboratory-based research into SKYCLARYS, and the clinical trial which took place in multiple countries including at the London Ataxia Centre. Prof Giunti works tirelessly for the ataxia community, and we want to thank her for all that she does and congratulate her and the rest of the team on this amazing achievement.

*For SKYCLARYS updates, register to receive our newsletter: [www.ataxia.org.uk/omav-updates](http://www.ataxia.org.uk/omav-updates)*



## Ataxia UK's updated research strategy

**Our ambition is to support the development of safe and effective treatments for the ataxias. Our Research Strategy, which guides the work of the Research Department, is an important plank in this aspiration. To view the full Research Strategy see: <http://alturl.com/g5dga>. Read on for a summary.**

**Funding projects:** Ataxia UK funds research projects on a wide range of ataxias, with the maximum potential of making an impact.

**Promoting ataxia research:** Interest in ataxia from pharmaceutical companies is growing. Ataxia UK often meets with companies to highlight this opportunity, and the impact they could make where there is a large unmet need. We play a pivotal role in assisting researchers, by providing information on research, ensuring the patient voice is included at all stages, and collecting data from people with ataxia.

**Supporting research projects:** We act as a partner to researchers applying for large multi-site grants from other funding bodies. Our involvement strengthens all stages of a project from providing the perspective of those with ataxia, to helping study recruitment.

**Involvement in research:** The impact of involving people affected by ataxia in research cannot be underestimated and we continuously seek ways of maximising engagement.

**Patient registries:** Registries are a vital resource for researchers, providing information directly from people living with ataxia. We are a lead organisation on The FA Global Patient Registry, and, with US Foundation CureDRPLA, we have launched The CureDRPLA patient registry. Registries for other ataxias are being considered.

**Representing people with ataxia in international projects:** Ataxia UK's Head of Research, Julie Greenfield, is on the Steering Committee for the Ataxia Global Initiative, which aims to prepare the ataxia field for clinical trials. We are also involved in the Critical Path Institute's ataxia consortium, which acts as the bridge between researchers and regulatory agencies.

**Putting the results of research into practice:** Turning research findings into practice is the ultimate step to ensuring that people with ataxia benefit from research. The Specialist Ataxia Centres and engagement of our Medical Advisory Panel assist us with this task. With the recent approval of the first drug for FA in the US we are working towards approval and access to the drug in the UK.

**Sharing research updates:** We work with other ataxia charities to organise the hugely successful International Congress for Ataxia Research Conferences, which play a significant role in driving research forwards. We also ensure that those affected by ataxia are kept informed of research developments. Our goal for the coming years is to bring the next conference to the UK.

# Ataxia UK funds project to improve the diagnosis and management of gluten ataxia

**Ataxia UK, Coeliac UK, the Sheffield Hospital Charity and the Greaves and Withey Foundation have awarded funding to Professor Marios Hadjivassiliou, Director of the Sheffield Ataxia Centre (right), Sheffield Teaching Hospitals NHS Trust, and colleagues, to help improve the diagnosis and management of gluten ataxia.**

Their aim is to develop a clear diagnostic pathway that can be used by neurologists so that more people with gluten ataxia can be diagnosed earlier. This is a collaborative project involving other Neurology Centres with an interest in ataxia across the UK, including the London and Oxford Ataxia Centres.

Gluten ataxia is caused by a sensitivity to gluten, which is found in wheat, barley and rye products. This sensitivity means that when people with gluten ataxia eat gluten, the body's immune system produces antibodies. These antibodies can then attack the balance centre of the brain and cause the symptoms of ataxia. Gluten ataxia can be treated by a strict gluten-free diet, which has been shown to stop the progression and potentially improve ataxia symptoms if started early enough. Therefore, early diagnosis of gluten ataxia is extremely important.

While some people with gluten ataxia will also have coeliac disease (inflammation of the small bowel causing abdominal pain, altered bowel habit, bloating and malabsorption), the majority do not, and will test negative in the widely available blood tests used to diagnose coeliac disease. Previous research by Professor Hadjivassiliou and colleagues showed that people with gluten ataxia have antibodies called tissue transglutaminase 6 (tTG6) and antigliadin antibodies present in their blood, and these can be tested in addition to the widely available coeliac blood tests to diagnose gluten ataxia. This testing is currently available in Sheffield under the NHS but not in other laboratories in the UK.

In this study, the Sheffield Ataxia Centre will work with other neurologists throughout the UK who have clinics for people with ataxia (London, Oxford, Manchester, Romford). People who have had tests to rule out other types of ataxia and who still do not have a diagnosis of the cause of their ataxia will be referred to the Sheffield Ataxia Centre to be tested for gluten ataxia. This will include tTG6 and antigliadin antibody tests and, if positive for these antibodies, a gut biopsy. Those diagnosed with gluten ataxia will be advised to follow a strict gluten-free diet. They will then be followed up after one year to assess the impact of the gluten-free diet. If you are interested in being involved in the project (and you are attending one of the centres involved), speak to your neurologist about taking part.





## Ataxia UK funds new project on less frequently studied symptoms of spinocerebellar ataxia

**As well as difficulties with co-ordination and balance, people with Spinocerebellar Ataxia Type 3 (SCA3) might experience other symptoms such as muscle cramps, pain, tingling, numbness, and loss of muscle mass. This is due to the common involvement of the peripheral nervous system, which are the nerves that branch out from the spinal cord to the limbs. So far very few studies have looked at how these symptoms change over time and whether they are associated with visible changes in the nerves and muscles.**

Ataxia UK has awarded funding to **Dr Roderick Maas and colleagues** (above) at Radboud University Medical Center in The Netherlands to use ultrasound to measure nerve sizes, muscle volumes, and muscle structures in the arms and legs of people with SCA3. This research is also being supported by the National Ataxia Foundation. The study will include 30 people with SCA3, 10 people who have the SCA3 mutation but have not yet developed ataxia symptoms, and 20 people without ataxia. After their initial measurements, participants will be followed up after 1 year to see if any differences detected by ultrasound change over time, and whether these changes are related to the severity of symptoms.

This work is important as it will increase our understanding of these other, often overlooked, symptoms of SCA3, as well as aiming to provide a sensitive measurement of SCA3 symptoms which could be used to test whether a treatment is working in future clinical trials. It also sets up a framework for carrying out this type of study in other types of SCA in the future.



## Optimal clinical pathway for people in England with rare neurological conditions

**The optimal clinical pathway sets out what good treatment, care and support looks like for people with neurological conditions, from those experiencing the first symptoms, to those that have lived with such conditions for a long time.**

When Ataxia UK was notified that a pathway was to be created for people with movement disorders, we successfully lobbied for a pathway for people with ataxia to be included. The pathway shows the ideal route to care within the NHS in England and emphasises the important role of Specialist Ataxia Centres.

The creation of this pathway was overseen by the National Neurosciences Advisory Group (NNAG), with support from NHS England, and input from Ataxia UK and ataxia specialists. *For more information see:* [www.ataxia.org.uk/research-news/optimal-clinical-pathway-for-people-in-england-with-rare-neurological-conditions](http://www.ataxia.org.uk/research-news/optimal-clinical-pathway-for-people-in-england-with-rare-neurological-conditions)



# The first 272 steps to greater awareness

You may have recently received a letter where we shared Ben's wonderful achievement of visiting all 272 London Underground stations to help raise awareness of the ataxias and accessible travel in the capital.

If he looks familiar to you, it's because his effort was hugely successful with coverage in news outlets including BBC, ITV London, Yahoo News and many more. We are so thankful and proud of Ben and his stellar work.

One of the key objectives of Ataxia UK's Strategic Plan is greater ataxia awareness. This is why our most recent appeal focuses on new ways of increasing awareness among medical professionals, and the general public. We hope it will bring about quicker, more accurate diagnosis.

In this appeal we are asking Friends to help support this mission. Ben's journey to diagnosis took fifteen long years, many misdiagnoses and feelings of frustration. He believes his circumstances would have been different and his diagnosis quicker if there was greater awareness. Donating to this appeal can help make a difference through supporting projects aimed at raising awareness. If you haven't received your email and letter about Ben's story, then you can visit our website at

<https://www.ataxia.org.uk/may-23/>

Ben documented his quest on his Instagram [@tube.snapper](#) where he took some stunning photos of all of the tube stations as he visited them. We urge you to visit his Instagram and share his photos to help raise even more awareness.

*If you want to find out more about how you can help raise awareness then contact the fundraising team on [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk) and stay tuned for information of the 2023 International Ataxia Awareness Day campaign!*



## The new Memorial Tree

**It is the nature of this field that many of our loved friends with ataxia are no longer here with us today. But that doesn't mean we ever forget them.**

Our deceased friends all had their own journeys with ataxia. Each story unique and each friend beautiful. We want to preserve that individual beauty. We are constantly being asked for ways of helping preserve the memory of those we have sadly lost over the years. We have listened to you and we have created an answer to them – the Memorial Tree.

This Memorial Tree will be a permanent fixture on the walls of the Ataxia UK office. Sitting in between two windows, blending into the meadow of trees in the background. It will be at the very heart of the main office, serving as a constant reminder to help drive progress forward.

Buying a leaf on the Memorial Tree will serve as a tangible memory of your loved one. All proceeds go back into supporting the mission and goals you share with Ataxia UK. Prices start from £100. Plans for the Memorial Tree are progressing quickly, and we hope to have the tree ready for blossoming with the names of your loved ones by the end of summer.

*To register your interest in memorialising your loved one, please email [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)*



## Want to be in with another chance of winning?

**With the Spring Raffle wrapped up, we wanted to thank you for taking part and getting your friends and family involved. Your support helped raise nearly £3000! Huge congratulations to all the winners! Keep an eye out on our Winter Magazine for details of the 2024 Spring Raffle...**

While the Raffle is over, our quarterly Chance2Win lottery is open throughout the year! The Chance2Win lottery is a great way to get involved with Ataxia UK through a regular donation, which helps support a number of projects. This includes research investments and it ensures support services reach those who need them, all the while you're in with the chance of winning one of three quarterly prizes, including the **top cash prize of £500!** Tickets cost just £2 a month and you can buy as many tickets as you like. The more tickets, the greater your chance of winning while also increasing vital support.

*For more information on joining our Chance2Win lottery, visit [www.ataxia.org.uk/chance2win](http://www.ataxia.org.uk/chance2win) or email [kfearnley@ataxia.org.uk](mailto:kfearnley@ataxia.org.uk) for more information.*

Chance2Win

WIN  
TOP CASH  
PRIZES

Chance2Win

WILL YOU  
BE THE NEXT  
WINNER?

# Fundraising thank-yous

From skydives to marathons, you have all been amazing. Working so incredibly hard, and we'd like to say a **BIG Thank You**.

Congratulations **Ashley Denton** (below) for completing the Yorkshire Marathon and raising a speedy £1,670.

A big cheer for **Carl Joyce (1)** who raised £758, by running the Cambridge Half Marathon with an extra 16kg weight!

Thank you so much **Tallulah Clark (2)** for celebrating her birthday with Ataxia UK and raising £456!

Happy 50th Birthday to **Riccardo Cucuzza (3)** and a big thank you to his sister **Roberta** for organising his Fundraiser, raising a fantastic £1,450.

**Kirsty Bennett's (4)** Danceathon was a spinning success, raising a fabulous £770, thank you.

Thank you **Joanne McDougall (5)** for raising £50 by dedicating a tree in memory of her friend **Shelley Marks** at the St Faiths Christmas Tree Festival.

A soaring congratulations to **Caroline Moss (6)** who completed the Velocity 2 Zipline, raising £300!

High-fives to **Jacob Bailey (7)** who ran 100 miles in a month raising £757.

A huge thank you to **Aileen Williams** and the construction plant company **Clee Hill** raising a glorious £500!

**Andrea Stephens (8)** handmade beautiful hedgehogs, selling them at a Fete and raising a wonderful £277.

**Emma Risley** zoomed to the finish line at the Sheffield Half Marathon raising an awesome £1,020.

A sky-high thank you to **Caitlin Wilson**, who completed a skydive with an amazing £2,500!

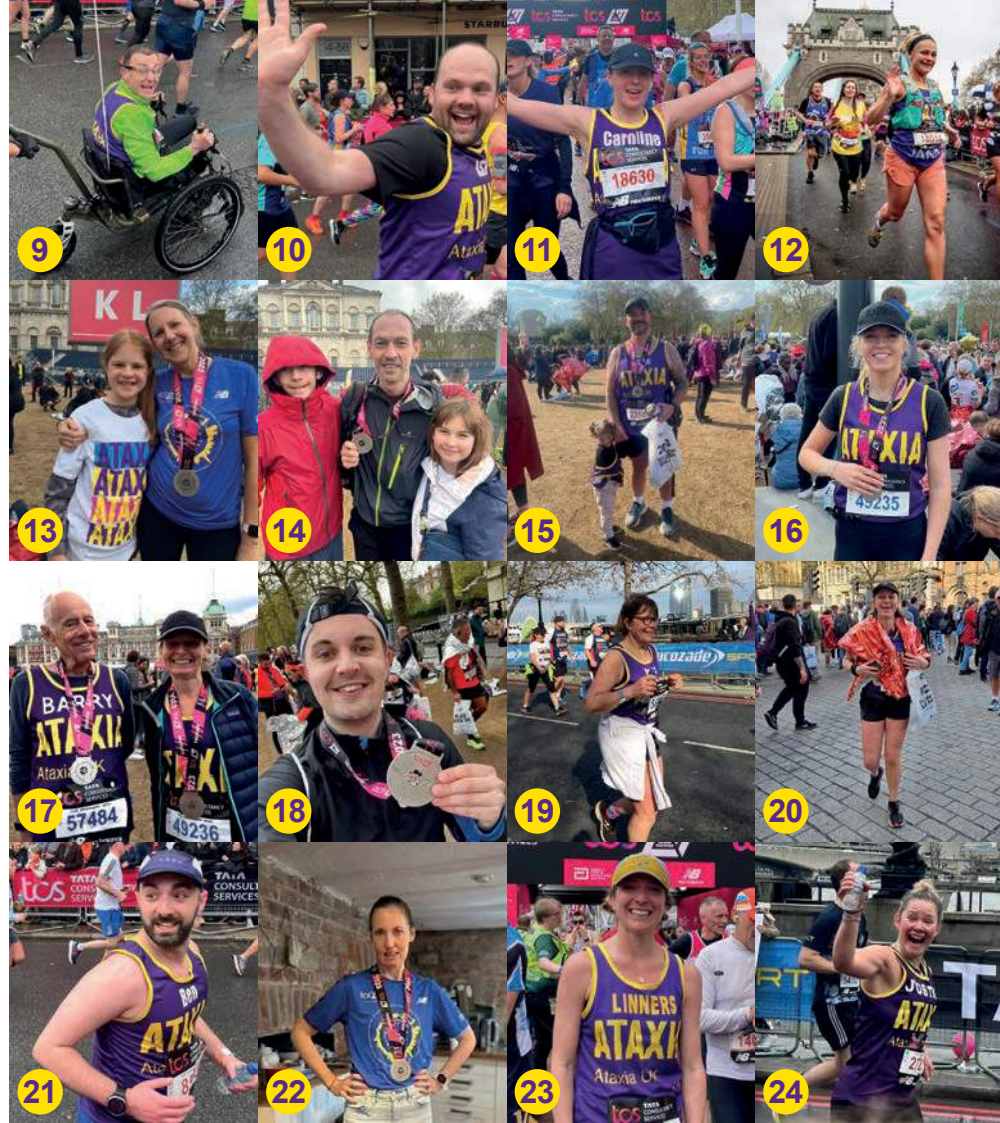


We couldn't be more thankful to our runners this year, you are all huge inspirations.

## London 2023 Marathon

A big cheer for our AMAZING London Marathon Runners **Geraint Williams (9)**, **Ashley Holdsworth (10)**, **Caroline May (11)**, **Jakki Floyd (12)**, **Karen Sedwick (13)**, **David Fraser (14)**, **James McKenna (15)**, **Phoebe Fenwick (16)**, **Abigail & Barry Hunt (17)**, **Matthew Siggins (18)**, **Joanne Chilcott (19)**, **Kate Lawson (20)**, **Ben Smyth (21)**, **Alex Wilson (22)**, **Lyndsey Boulter (23)** and **Justine Ellory (24)**.

Congratulations to this epic team for making it to the finish line and raising over £27,000! What an epic effort, thank you Team.



## London Landmarks Half Marathon

Congratulations to **Amanda Halliday, Dawn Corlet & Victor Choules (25)**, **Scott Renton (26)**, **Jim Hunter & Melanie Ditch (27)**, **Stephanie Gale (28)**, **Corrie Gillies (29)**, **Harry Brazier (30)**, **Aleisha White, Kaisha Palmer, Aiden Palmer & Lucy Smith (31)**, **Milly Sayer-Pardoe (32)** and **Beth & Felicity Baines (33)**!

Starting the race at Pall Mall, they zipped by Nelson's Column, whizzed past the halfway point at St Paul's Cathedral and sped through the finish line to collect their medals, right by Downing Street!

Collectively they raised over £19,000!





# Ataxia Classic 2023

**Take to the beautiful Yorkshire roads on Sunday 24th September as we cycle towards a cure together!**

With a fully accessible 12km route, a 51.6km and a 102km route, whether you are a Pedal Pro or a Biking beginner, fancy a challenge or just want to be part of an awesome team, this cycle is for you!

Based out of the charming market town of Pocklington, you'll cycle through the rolling hills of the East Riding of Yorkshire and parts of the renowned Tour de Yorkshire whilst absorbing the spectacular scenery. The Ataxia Classic will raise crucial funds, and as we welcome you to the team we will be with you every pedal of the way.

There will be refreshments before you set off and food and drinks to welcome you back before you collect your well-deserved medal! We welcome Friends and Family on the day, and it promises to be another brilliant day full of camaraderie.

Riders for the fully accessible route must be aged 11 years or over, and for the medium and long routes, aged 14 years or over. All riders under 16 must be accompanied by an adult.

Register now: <https://ataxia.org.uk/ataxia-classic-2023/>  
or contact us: [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)

"We thoroughly enjoyed the day, and big thanks for organising such a great event. The highlight was the friendliness and camaraderie of the cyclists who stopped to chat with my son, who has Friedreich's Ataxia, and my two daughters who were on the route cheering..." **Stephen**

**This September, be part of #TeamAtaxiaUK and make it the best Ataxia Classic yet!**



## Virtual art exhibition 'Through My Gaze' 2023

**With over 40 contributing artists from hobbyists to professionally trained, including those who have exhibited internationally, the exhibition was a great success raising over £1,600! We couldn't be more grateful for the kind contributions, and to everyone who purchased an artwork.**

"I think your project is of great value and hope it does very well given the particularly difficult times so many experience today in our increasingly fragmented society." - **John Wallett, Artist.**

"I definitely made the right choice. I love Lisa's expression and work - the colours are amazing. The more I look at it, the more I see."  
- **Sara Upton Le-Hair, Buyer and Artist.**

Find out more here:

[www.ataxia.org.uk/throughmygaze](http://www.ataxia.org.uk/throughmygaze)  
and if you missed the Exhibition, don't worry!  
All remaining art will be sold at a future event.



## Enjoy the ride, savour the moment & ride on!

**Calum O'Neill, a 25-year-old paracyclist with ataxia from East London, is training extremely hard for the Great Britain Cycling Team. Calum kindly agreed to share his inspiring paracycling journey...**

Calum's ataxia journey began when he was only 18 months old. He became unwell and started to develop strange eye movements. They discovered this was a precursor to his immune system and put his health at risk. Calum was rushed to Great Ormond Street Hospital. He says, "Within days, my parents were told I had a condition called Dancing Eye Syndrome (Opsoclonus myoclonus) and consequently developed associated learning difficulties and dyspraxia." As a result, Calum was late to talk and walk.

Calum attended a mainstream school until he was seven, then "my learning difficulties needed further support, and I was told I also had dyscalculia." Despite school life being challenging for Calum, he did his best. He passed as many qualifications as possible within a supported environment, finishing with a personal trainer qualification.

Calum says: "I gradually worked my way through. Rugby? Not physically strong enough, running wore out my ankles. Swimming? I drank most of the pool! But cycling has always been there, even though I noticed I bumped into people in crowds and was a bit off-balance. 2020 was the year I really noticed I could not walk in a straight line. To compound the problem, I encountered problems riding a two-wheeled bicycle. My parents had seen me have spectacular falls at home for no reason and urged me to seek medical advice when I was 22." After thorough investigations, he was put under the care of the Queens Square Neurological Team and was diagnosed with ataxia. Tests are still ongoing to determine what type.

Calum is a motivated young man who strives to be his best version. He puts it, "I have poor hand and balance skills. Standing for lengthy periods of time and walking is difficult for me, and I still fall. But I have always managed to work, and I'm currently employed by Sustrans and Bikeworks, which involves interaction with clients which I enjoy."

He trained intensively to be selected for the Great Britain Para-Cycling Development program, and he successfully claimed his place. He says: "Finding out I had been selected was quite simply amazing! In 2021 I had to move to ride a trike, and it was like a huge weight had been lifted off my shoulders, and I realised that I had done what I was capable of and really wanted. I proved to myself that I was finally good at something. Even though I was so ecstatic with my happiness, I was nervous knowing the challenging work had only just begun. I knew that at the next camp, I would have to prove that that was no fluke. I could back it up again."

Here's some advice Calum would like to share with the Ataxia UK community: "The best bit of advice I can give you is to dream big and work hard every single day because it will pay off in the end. My strength and training regime are keeping me moving despite my ataxia. The second bit of advice I will give you is to never listen to people who say you cannot. Instead, always aspire to bigger, better things but ensure you always stay grounded. And lastly, enjoy the ride, savour the moment and always ride on!"



# Travelling and ataxia

There are lots of different websites offering information to get you thinking about and planning your holidays whether that be abroad or in the UK. There is advice on researching and planning your trips, your rights as a disabled person with reduced mobility, accommodation, health and medication. We've collated just a few to get you started.

- Gov.uk information on travelling abroad with a disability, as well as a great general guide it has information on how to contact the nearest British embassy, high commission or consulate:  
**[www.gov.uk/government/publications/disabled-travellers](http://www.gov.uk/government/publications/disabled-travellers)**
- Using your Blue Badge in Europe since BREXIT: **<http://alturl.com/u5mvw>**
- Tourism for all – disabled-friendly accommodation, attractions and places to eat and drink: **[www.tourismforall.co.uk](http://www.tourismforall.co.uk)**

There are also a lot of specific travel companies, as well as many mainstream ones catering for holidays for the disabled from cruises, to adapted mobile homes to wheelchair-friendly hotels and cottages.

## DISABLED HOLIDAYS

Caters for all kinds of breaks and holidays from the UK to Europe and long haul. they will also sort out flights adapted transfers and equipment:  
**[www.disabledholidays.com](http://www.disabledholidays.com)**

## ENABLE HOLIDAYS

Tailor-made holidays to suit your specific needs: **[www.enableholidays.com](http://www.enableholidays.com)**

## REVITALISE

Offer respite holidays for disabled people and their carers in the UK:  
**<https://revitalise.org.uk/respite-holidays>**

## TUI

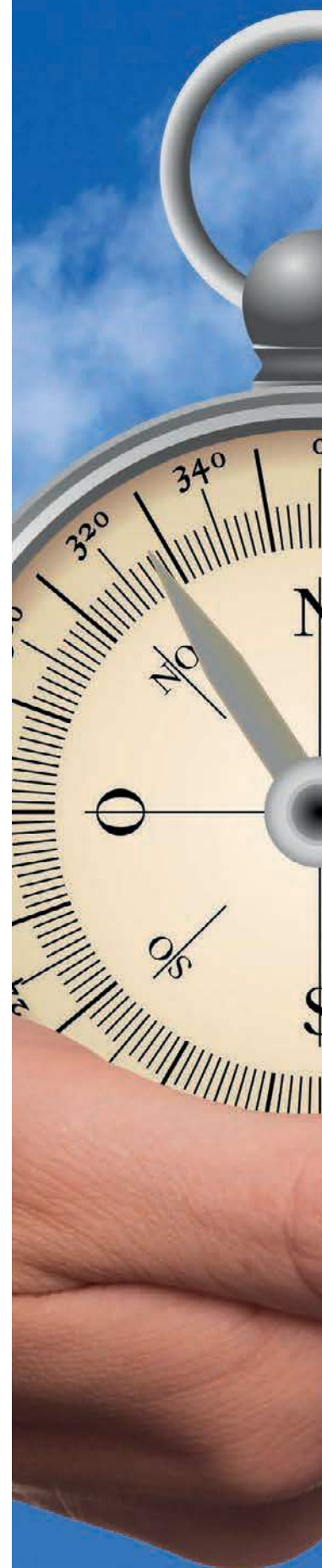
Offer a wide range of holidays and cruises for people with a disability or reduced mobility: **[www.tui.co.uk/holidays/accessible-holidays](http://www.tui.co.uk/holidays/accessible-holidays)**

When travelling in the UK and Europe if you have a disability or reduced mobility, you have the right to free assistance at terminals and whilst on board, for all forms of travel. This is not always the case across the rest of the world and something you will need to check when travelling long-haul. Assistance can be booked through the airport/terminal you are using. British Rail have created an app that you can use to book assistance when travelling by train: **<http://alturl.com/c3h47>**

## TRAVEL INSURANCE

There are lots of travel insurers that specifically cover people with disabilities. Google is a good place to start. Here are some things to consider:

- You may already be covered by your bank account, although don't forget to tell them about your medical condition.



- Single-trip policies might be cheaper than annual policies.
- Family or group policies are based on the traveller deemed the highest risk, so consider separate cover.
- Planning a cruise? you will likely need an add-on to the policy.
- Are you going to Europe? Don't forget your free **EHIC/GHIC** as it can help with medical costs: <http://alturl.com/mjsk8>
- As ataxia is so rare it is a good idea to phone up your chosen insurer and make sure that they cover ataxia. You might also want to consider sending them some information on ataxia. We can help you with this, just contact the Helpline.

*Money Saving Expert has lots of information and tips on travel insurance for pre-existing conditions: <http://alturl.com/fwoj7>*

### TRAVELLING WITH YOUR PET



**Helpline Volunteer Mark (left) travels with his dog and has shared some helpful tips. You may want to bring your pet abroad with you, it's possible but requires planning. These are the rules for travelling to Europe with a pet, please check if you want to take your pet further afield!**

Pets must be microchipped, wormed (for some countries) and vaccinated against rabies (they must be at least 12 weeks old for vaccination and be vaccinated at least 21 days before you travel). You will need an AHC (Animal Health Certificate) from your vet at least 10 days before you travel to the EU or Northern Ireland. Costs vary but rabies vaccinations cost around £65 and an AHC could set you back £100-£200.

You also need to consider insurance for your pet, is your pet's insurance valid overseas?

Think about food, treats and water both whilst you are travelling and when you get there (you can't take UK food which contains meat products, but you can try gradually weaning them onto vegetarian treats/food beforehand).

**You need to decide how you will travel with your pet.** Should you want to fly, airlines all have different rules regarding weight, carrying vessel, but as a rule they can travel with you in the cabin if under 6kg and in the correct crate, or then are placed in the hold, though some animals may find that stressful. Or you might prefer (as I do) to travel by train.

Most European countries have very dog and pet-friendly train services. There are rules of travel so research them in advance (for example in some places dogs have to be muzzled on public transport). You may have to buy a pet ticket, depending on how you travel. There's lots to think about but, we have some links which you might find useful:

[www.comparethemarket.com/pet-insurance/content/pet-passport](http://www.comparethemarket.com/pet-insurance/content/pet-passport)

[www.gov.uk/taking-your-pet-abroad/getting-an-animal-health-certificate](http://www.gov.uk/taking-your-pet-abroad/getting-an-animal-health-certificate)

*If you have any questions about travel, please contact the Ataxia UK Helpline at: **0800 995 6037** or email [help@ataxia.org.uk](mailto:help@ataxia.org.uk)*

## London Fashion Week in wheels

**Our Friend Dee shares her remarkable story of modelling at the London Fashion week. To read her full blog, head over to: [www.ataxia.org.uk/your-blog/fashion-week-in-wheels-dee](http://www.ataxia.org.uk/your-blog/fashion-week-in-wheels-dee)**

There I was. A wheelchair-using woman about to enter the Kurt Geiger showroom, about to model for a new disability-inclusive brand for their first runway show called **Unhidden** in the centre of London. Sounds like a dream, right? Except it wasn't. This was real life with me at the centre. I was a little fish in a very big pond. Thank God my sister-in-law was with me as my anxiety was through the roof, tempting me to bolt. However, within ten minutes, I was getting my hair curled and being talked to by the stylist like we were best friends. My anxiety waned. Then makeup. My anxiety waned further. And not once did I have to adapt or accommodate my disability. They adapted around me. No condescending questions asked. I was 'normal' for once, like everybody else.

Every model I met was open, receptive, kind and wonderful. Each person had their own disability. Their own story. Their own path to walk... Runway to walk. Anxiety dissipated until the runway rehearsal. All lined up, waiting for our minute when all eyes will be on us, the clothes and our disabilities. Four rehearsals down, the clock was ticking down till the actual show. Before I could even blink, we were in beautiful, adaptive, comfy clothing fitting everyone's needs and disabilities perfectly! Victoria: the creator and designer did an amazing job!

For society to see us and accept all disabilities are normal and deserving of fashion that fits us, whilst looking stunning on. My minute on the runway went by in a blink... Rather it felt that way. At that moment, I was a model. I am a model! A wheelchair-using, disabled model. 10 years ago, that would've been unheard of. But here I am! Here we are! This show kicked the door open by showing everyone in the industry disabled people are beautiful, too and deserve to be shown.

My advice to anyone with Ataxia who is daydreaming of doing something like this but thinks it's only a dream. Do it! It's not a dream! It's not impossible! Ignore that little voice inside your head that tells you, 'You can't' or 'People will judge you.' Who cares? Don't let a stranger's 2-second thought become your entire reason for not living. Go for whatever you want to do! I did, and I am ecstatic I did. The career and possibilities are endless. As they will be for you if you just take that leap of faith in yourself and what you're capable of.



# How to apply for a grant

**Grants can help people who are struggling financially to pay for specific items such as motorised wheelchairs and other aids, respite care and holidays, gym memberships and lots of other things. Grants do not usually give general financial assistance.**

There are lots of grant funds out there but they are all restricted to fund certain things or people, and some cover specific geographical areas. The best place to start is an online grant finder, like this one from Turn2Us:

**<https://grants-search.turn2us.org.uk>** or Disability Grants: **[www.disability-grants.org](http://www.disability-grants.org)** which also has some helpful tips.

In many cases, grant-giving organisations will not accept applications from the general public, and insist on referrals and requests from professionals, organisations and charities like Ataxia UK.

There are 3 grant-giving organisations Ataxia UK works with. For more information, please visit: **[www.ataxia.org.uk/support-services/grants](http://www.ataxia.org.uk/support-services/grants)**. Additionally, our team is here to help you apply to other organisations.

The cost-of-living crisis has impacted on grant funds, award amounts have decreased and the number of applications to each organisation has gone up.

**Depending on the cost of the item or service you are hoping to secure, you may need to think about applying for more than one grant.**

You will also need to look at what kind of supporting evidence each organisation asks for to support your application. Not all organisations ask for the same things but the sort of things that you might be asked for are – medical letter with diagnosis, third party letter of support, supplier's quote, proof of benefits and confirmation that the funding isn't available from other sources like the NHS.

Please bear in mind when applying for grants that it is not a quick process. It takes time to find the right grants, to fill in the application forms with the help of a third party and gather all the supporting evidence. When the application is put in and accepted it can take a couple of months to get a decision. Although organisations will normally let you know roughly what timeframe to expect.

**Ataxia UK has helped to secure nearly £7,000 in grant funding for Friends of Ataxia UK in the last 12 months.**

*Our Helpline team can help you at any point in this process and has lots of knowledge about different grants. If you are struggling to find something suitable, or if you need help with the application process, please get in touch at **[help@ataxia.org.uk](mailto:help@ataxia.org.uk)** or **0800 995 6037**.*



# Scottish Advice Service

**Ataxia UK is thrilled to be working in partnership with Parkhead CAB in Glasgow to provide a new Scottish Advice Service, tailored to meet the needs of people affected by ataxia in Scotland.**

Research has shown that mainstream advice services do not successfully meet the needs of the Ataxia Community, due to a lack of knowledge about ataxia and the impact it has on the lives of those affected by the condition.

**In our survey, looking at the financial issues facing people with ataxia (AUK FI 2019/20) we learned:**

- 68% reported not getting help to apply for benefits, with just under half of these respondents feeling this would have helped them (AUK FI).
- 44% rated the advice services they had accessed as being only satisfactory or worse in taking account of their needs (AUK FI).

**We are delighted to welcome our Rare Conditions Adviser, Eilidh Clark (right) to the Ataxia UK family.** Eilidh will be employed by Parkhead CAB and will work closely with the Ataxia UK Helpline Team to provide information, advice and support to people affected by ataxia in Scotland.

**The service aims to enable the Ataxia Community in Scotland to:**

- Access appropriate care and treatment.
- Increase their income and reduce the impact of income loss by accessing benefit entitlements and dealing with money and debt issues.
- Plan financially for the future.
- Deal with housing issues and make appropriate housing choices.
- Deal with employment issues, including working hours, retirement, and reasonable adjustments.
- Enable them to navigate the NHS and access therapies mitigating the physical impact of their condition.

The service will provide phone, online and face-to-face advice to people with ataxia, their families and carers, alongside a variety of online and face-to-face outreach activities linking to Ataxia UK's local Ataxia Support Groups and programme of virtual activities.

*If you live in Scotland, or if you know someone with ataxia who does, please do get in touch. You can reach the Scottish Advice Service, either by contacting **Eilidh** directly on [ataxia@parkheadcab.org.uk](mailto:ataxia@parkheadcab.org.uk) or via the Ataxia UK Helpline at: [help@ataxia.org.uk](mailto:help@ataxia.org.uk) / 0800 995 6037.*

citizens  
advice  
scotland

ATAXIA



# #VolunteersWeek

*"It is a belief in the extraordinary ability to touch, with goodness and compassion, the lives of others, and to shine a light in the world around them. This is the essence of our community and the very foundation of our society." King Charles III; The King's Christmas Broadcast 2022*

**Every year, Volunteers Week takes place between the 1st and 7th of June. Hundreds of charities come together to recognise, celebrate and showcase their volunteers, their contributions and the impact volunteering has on the community.**

Since the beginning of the InControl Project, we have now recruited and support over 100 volunteers spread across the UK. Through their many different roles, our volunteers provide peer support, information, friendship & a listening ear to our service users. **This year, in celebration, we are hosting two events for our volunteers:**

**Thursday 1st June at 1pm Volunteers Week quiz**, with Quiz Master and Helpline & Advocacy Officer, Jessica. *Register here if you want to join!* <http://alturl.com/kqse8>

**Tuesday 6th June at 11.30am - free Chair Pilates session with Sonia Ford.**  
*Register here if you want to join!* <http://alturl.com/phsgt>

It goes without saying that our volunteers have played and continue to play a vital role in helping us develop and deliver services that are needed to the ataxia community. We are grateful for each and every one of you and appreciate the time you give up and effort you put in to raising awareness of ataxia & fundraising, and the friendship and light you provide to those who are struggling, newly diagnosed or isolated.

Happy Volunteers Week!  
You are the beacon of light leading the way and we couldn't do this without you. From all of us here at Ataxia UK & on behalf of the ataxia community.

**Thank you,  
The Services Team**

*"We have so many volunteers committed to strengthening the support we provide. The huge range of skills comes together to support the work we do, the volunteers are an absolutely essential component. So if you volunteer for Ataxia UK, thank you so very, very much for the time and energy you devote."*

**Sue Millman**

If you are interested in volunteering with us, please have a look at our available roles, here:  
<http://alturl.com/q5z8u> or email [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)

# Thank you!

to all our amazing volunteers





Thank you  
to everyone  
who has given  
a donation  
in memory of  
a loved one

Leaving a legacy  
is one of the most enduring ways  
to make an impact

Much of our research  
has been made possible  
by the foresight and generosity  
of our Friends and supporters  
who have remembered our work  
when making their will

We currently have several  
research projects underway,  
some of which are funded,  
at least in part, by gifts left to us.

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**Your legacy can be hope for the future**